Title: Evaluating Patients' Unmet Needs in Hidradenitis Suppurativa: results from the Global VOICE project

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Manuscript count: 2500

Capsule summary: 36

Abstract count: 199

Figures: 0

Tables: 5

References: 72

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Funding Sources: None.

Conflict of Interest:

Oleg Akilov

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Afsaneh Alavi

Dr. Alavi reports grants and personal fees from Abbvie, personal fees from Galderma, personal fees from Janssen, personal fees from LEO Pharma, personal fees from Novartis, personal fees from Sanofi Aventis, personal fees from Valeant

Christine Ardon

Dr. Ardon has nothing to disclose.

Christina Avgoustou

Dr. Avgoustou has nothing to disclose.

Falk G. Bechara

Dr. Bechara reports grants from AbbVie, grants from Novartis, grants from Inflarx, grants from Janssen

Denny Cha

Denny Cha has nothing to disclose.

Arnon D. Cohen

Prof. Arnon Cohen received research grants from Janssen, Novartis and AbbVie and Sanofi.

Prof. Arnon Cohen served as a consultant, advisor or speaker to AbbVie; Amgen; Boehringer Ingelheim; Dexcel pharma; Janssen, Lilly; Neopharm; Novartis, Perrigo; Pfizer; Rafa; Sanofi

Steven Cohen

Dr. Cohen reports grants from Abbvie Pharmaceuticals, and Honoraria from Verrica Pharmaceuticals

Steven Daveluy

Dr. Daveluy reports personal fees from Abbvie, other from InflaRx

Véronique del Marmol

Dr. del Marmol reports grants from ABBVIE, personal fees from SANOFI

Maia Delage

Dr. Delage has nothing to disclose.

Solveig Esmann

Dr. Esmann has nothing to disclose.

Shani Fisher

Dr. Fisher has nothing to disclose.

Amit Garg

Dr. Garg reports personal fees from Asana Biosciences, personal fees from Amgen, personal fees from AbbVie, personal fees from Janssen, personal fees from UCB, grants from National Psoriasis Foundation, grants from AbbVie

Evangelos Giamarellos-Bourboulis

Dr. Giamarellos-Bourboulis reports personal fees from AbbVie Inc, grants and personal fees from XBiotech, grants and personal fees from InflaRx GmbH, grants from bioMerieux, grants from Abbot CH, personal fees from MSD Hellas, grants and personal fees from Biotest GmbH, grants from Marie Curie Grant European Sepsis Academy, grants from FP7 project hemoSpec, personal fees from Pfizer Hellas, grants from Astellas Pharma Europe

Amelia Glowaczewska

Dr. Glowaczewska has nothing to disclose.

Noah Goldfarb

Dr. Goldfarb has nothing to disclose.

Elena Gonzalez Brant

Dr. Gonzalez Brant has nothing to disclose.

Øystein Grimstad

Dr. Grimstad has nothing to disclose.

Iltefat Hamzavi

AbbVie, Advisory Board, No Compensation Received; Clinuvel, Principal Investigator, Research Funding to Institution; Estee Lauder, Principal Investigator, Research Funding to Institution; Janssen Biotech, Principal Investigator, Grants/Research Funding to Institution; Pfizer Inc., Principal Investigator, Research Funding to Institution; Bayer, Principal Investigator, Grants/Research Funding to Institution; Lenicura, Principal Investigator, Equipment provided to Institution; Allergan, Principal Investigator, Research Funding to Institution; GE, Principal Investigator, Research Funding to Institution; Johnson & Johnson, Principal Investigator, Equipment to Institution; Incyte, Principal Investigator, Research Funding to Institution; Incyte, Personal Consultant Fees; Pfizer, Personal Consultant Fees; UCB, Personal Consultant Fees; HS Foundation, President, Non-compensated role; Global Vitiligo Foundation, Co-Chair, Non-compensated role; AbbVie Esprit/P10-023, Principal Investigator, Research Funding to Institution; AbbVie HS Registry/H13-147, Sub Investigator, Research Funding to Institution; Bristol-Myers Squibb (IM011047), Sub-Investigator, Research Funding to Institution, Corrona/PSO-500, Sub-Investigator, Research Funding to Institution; Eli-Lilly/14V-MC-JAIW, Sub-Investigator, Research Funding to Institution, Eli-Lilly/14V-MC-JAIX, Sub-Investigator, Research Funding to Institution, Janssen Psolar/CO168Z08, Principal Investigator, Research Funding to Institution, Janssen/(CNTO1959PSO3002), Sub-Investigator, Research Funding to Institution; Janssen (CNTO1959PSO3009), Sub-Investigator, Research Funding to Institution; Janssen (CNTO1959HDS2001), Sub-Investigator, Research Funding to Institution; Merck/MK-3200-011, Sub-Investigator, Research Funding to Institution.

Rosalind Hughes

Dr. Hughes has nothing to disclose.

John R. Ingram

Dr. Ingram reports personal fees from UCB Pharma, other from Abbvie, personal fees from Novartis.

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Dr. Jemec reports grants and personal fees from AbbVie, personal fees from Coloplast, personal fees from Pierre Fabre, grants and personal fees from InflaRx, grants and personal fees from Leo Pharma, grants and personal fees from UCB, grants from Janssen-Cilag, grants from Regeneron, grants from Sanofi, grants from Astra Zeneca, other from Miiskin

Qiang Ju

Dr. Ju has nothing to disclose.

Naomi Kappe

Dr. Kappe has nothing to disclose.

Brian Kirby

Dr. Kirby reports grants, personal fees and non-financial support from Abbvie

Joslyn Kirby

Dr. Kirby reports personal fees from AbbVie, personal fees from Incyte, personal fees from ChemoCentryx

Michelle A. Lowes

Dr. Lowes reports personal fees from Abbvie, personal fees from Incyte, personal fees from Xbiotech, personal fees from Janssen

Lukasz Matusiak

Dr. Matusiak has nothing to disclose.

Robert Micheletti

Dr. Micheletti has nothing to disclose.

Dagfinn Moseng

Dr. Moseng has nothing to disclose.

Haley Naik

Dr. Naik has nothing to disclose.

Aude Nassif

Dr. Nassif has nothing to disclose.

Erica Neuren

Erica Neuren has nothing to disclose.

Georgios Nikolakis

Dr. Nikolakis has nothing to disclose.

So Yeon Paek

Dr. Paek has nothing to disclose.

Jose Pascual

Dr. Pascual has nothing to disclose.

Errol Prens

Dr. Prens has nothing to disclose.

Barry Resnik

Dr. Resnik reports personal fees from AbbVie

Hassan Riad

Dr. Riad has nothing to disclose.

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Dr. Sayed reports personal fees from Abbvie Inc, personal fees from Novartis, other from InflaRx, other from UCB

Saxon D. Smith

Dr. Smith reports personal fees from ABBVIE, other from ABBVIE, personal fees from ABBVIE

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Yssra Soliman has nothing to disclose.

Andrew Strunk

Andrew Strunk has nothing to disclose.

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Dr. Szepietowski reports personal fees from Abbvie, personal fees from Novartis, personal fees from Pierre-Fabre, personal fees from Menlo Therapeutics, personal fees from Sienna Biopharmaceuticals,

personal fees from Leo Pharma, personal fees from Trevi, personal fees from Sandoz, personal fees from Sanofi Genzyme, personal fees from Janssen-Cilag, personal fees from Amgen, personal fees from Galapagos, personal fees from InflaRx, personal fees from Regeneron, personal fees from UCB.

Jerry Tan

Dr. Tan has a patent Copyright holder for HSQoL and HiSQoL with royalties paid.

Linnea Thorlacius

Dr. Thorlacius has nothing to disclose.

Thrasyvoulos Tzellos

Dr. Tzellos reports grants and personal fees from Abbvie, grants and personal fees from UCB

Hessel van der Zee

Dr. van der Zee reports personal fees from ABBVIE, personal fees from INFLARX, personal fees from NOVARTIS, personal fees from GALDERMA

Bente Villumsen

Dr. Villumsen has nothing to disclose.

Lanqi Wang

Dr. Wang has nothing to disclose.

Christos Zouboulis

Dr. Zouboulis reports personal fees from AbbVie, personal fees from AbbVie, grants from AbbVie, personal fees from Idorsia, personal fees from Inflarx, grants from Inflarx, personal fees from Novartis, grants from Novartis, personal fees from UCB, grants from UCB, other from Incyte

Role of Sponsor: NA

Prior Presentation: There is no prior presentation of this work.

IRB Statement: This investigation was approved by the IRB of the Feinstein Institute for Medical Research at the Northwell Health.

Acknowledgements: none

347

348 **Acronym List**

349 Global VOICE: Global Survey Of Impact and Healthcare Needs

350 HS: hidradenitis suppurativa

351 QOL: quality of life:

352 HiSQOL: Hidradenitis Suppurativa Quality of Life

353 SES: socioecomonic status

Abstract:

Background: A needs assessment for patients with hidradenitis suppurativa (HS) will support advancements in multidisciplinary care, treatment, research, advocacy, and philanthropy.

Objective: To evaluate unmet needs from the perspective of HS patients.

Methods: Prospective multinational survey of patients between October, 2017 and July, 2018.

Results: Majority (63.7%, n=827) visited a physician ≥5 times prior to receiving formal HS diagnosis. Mean delay in diagnosis was 10.2 years (+/- 8.9 years). Patients experienced flare daily, weekly, or monthly in 23.0%, 29.8%, and 31.1%, respectively. Most (61.4%, n=798) rated recent HS-related pain as moderate or higher, while 4.5% described recent pain to be worst possible. Access to dermatology was rated as difficult by 37.0% (n=481). Patients reported visiting the emergency department and hospital ≥5 times for symptoms in 18.3% and 12.5%, respectively. An extreme impact on life was reported by 43.3% (n=563), and 14.5% were disabled due to disease. Patients reported high frequency of comorbidities, most commonly mood disorders. Patients were dissatisfied with medical or procedural treatments in 45.9% and 34.5%, respectively.

Limitations: Data was self-reported. Patients with more severe disease may have been selected.

Conclusions: HS patients have identified several critical unmet needs that will require stakeholder collaboration to meaningfully address.

Introduction

Hidradenitis suppurativa (HS), also known as acne inversa, is a potentially debilitating inflammatory disease that is linked to significant comorbidity burden[1] and overall mortality,[1-3] and that is also known to have substantial impact on general health-related and skin-specific quality of life (QOL).[4,5] Its inherent unpredictability with respect to disease course and treatment response poses challenges for patients and physicians. The purpose of the Global Survey Of Impact and Healthcare Needs (Global VOICE) project was to evaluate unmet needs in HS from the perspective of patients with the goal of supporting awareness initiatives in public and medical sectors, multidisciplinary approaches to care, advances in treatment, development of the research agenda, as well advocacy and philanthropy efforts.

Methods

Global affiliates from 27 institutions, most of which were HS referral centers, in 14 countries across four continents agreed to prospective recruitment of participants between October, 2017 and July, 2018. All patients at the center were offered an opportunity to participate, and there was no selection for disease stage. The questionnaire distributed to participants was developed by content experts and by patients with the disease in their capacity as research partners. It comprised 50 questions designed to capture demographics, perspectives on diagnosis and care, pain and symptoms, life impact, comorbid conditions, and treatment. Life impact was assessed using a disease-specific QOL instrument called the Hidradenitis Suppurativa Quality of Life instrument (HiSQOL).[5,6] This study received approval from the human subjects committee of the Feinstein Institute for Medical Research at Northwell Health.

Statistical Analysis

There were 1,927 surveys returned, of which 1,299 surveys met inclusion criteria of being completed by a patient diagnosed with HS by a licensed healthcare provider and having a response to all variables of interest. Complete case analysis was performed. Categorical variables were described as frequencies and percentages, while means (standard deviation) were used to describe continuous variables. We assessed association between self-reported delay in diagnosis and age using ANOVA.

Results

Patient Characteristics

Characteristics of Global VOICE participants are described in **Table I.** Participants were mostly from Europe (55.4%) and North America (38.0%), and were mostly aged less than 40 years (61.3%), female (84.9%), and white (80.6%). Participants looking for work reported being unemployed in 9.6% of cases, and another 14.5% reported being disabled and unable to work due to HS.

Diagnosis and Care

Mean age at onset of symptoms was 20.5 (+/- 9.3) years while mean age at diagnosis was 30.7 (+/- 10.9) years. Mean delay from onset of symptoms to diagnosis was 10.2 years (+/- 8.9 years). The majority of participants visited a physician for symptoms ≥5 times (63.7%, n=827) or 3-4 times (17.4%, n=226) prior to receiving a formal HS diagnosis. For 54.4% of participants (n=707), diagnosis was made by a dermatologist. For 59.8% (n=777) of participants, a dermatologist was the main physician managing their HS. However, 37.0% (n=481) of participants rated access to their dermatologist as difficult or very difficult. For symptoms related to HS, participants reported visiting the emergency department >5 times (18.3%, n=238), 4-5 times (7.7%, n=100), 2-3 times (17.2%, n=224), and once (16.3%, n=212).For symptoms related to HS, participants reported having been hospitalized >5 times (12.5%, n=163), 4-5 times (4.5%, n=59), 2-3 times (11.5%, n=149), and once (15.9%, n=206).

Pain and Symptoms

On the Numeric Rating Scale (NRS) for pain, 61.4% (n=798) of participants rated HS-related pain over the past week as moderate or higher (NRS score ≥5). Participants described worst possible pain (NRS score 10) in 4.5% (n=59) of cases. Only 9.0% (n=117) of participants described no pain (NRS score 0) over the past week. Mean NRS score 5.0 (SD=2.8).

Participants also described the following symptoms related to HS over the past week: drainage (71.8%, n=933); odor (53.8%, n=699), and fatigue (61.0%, n=793). A flare was experienced daily (23.0%, n=299), weekly (29.8%, n=387), or monthly (31.1%, n=404) in most participants.

Life Impact

Table II lists items and corresponding impact on QOL for participants. Most participants reported that HS impacted their lives moderately (27.2%, n=353) or very much/extremely (43.3%, n=563) in the past week.

Comorbid Conditions

Comorbid conditions among participants are described in **Table III**. Anxiety (36.2%) and depression (35.8%) were most frequently reported. Some other notable comorbid conditions reported were suicidal ideation or attempt (9.1%), infertility (5.7%), spondyloarthritis (5.5%), inflammatory bowel diseases (5.3%), substance abuse (3.6%), and sexual dysfunction (3.5%).

Treatment

Participants were dissatisfied or very dissatisfied with current treatment in 45.9% (n=596) of cases. Among those dissatisfied, reasons for dissatisfaction included poor efficacy (42.1%, n=547), undesirable side effects (18.9%, n=246), expense (10.5%, n=136), inconvenience (10.2%, n=132), and invasiveness (7.5%, n=98). With respect to procedural treatments, 29.3% (n=380) of participants reported feeling satisfied or very satisfied, while 34.6% (n=449) reported feeling dissatisfied or very dissatisfied. Level of optimism for having satisfactory control of symptoms within the next 3 months was low or very low in 45.9% (n=596).

Table IV describes frequency of medical and procedural treatment among participants. Most frequent medical treatments included oral antibiotics (85.6%, n=1,112) and intralesional corticosteroid (24.9%, n=323). Participants used a biologic in 20.8% (n=270) of cases, with adalimumab being the most frequent (16.0%, n=208). Participants used anti-androgen therapy in 12.7% (n=165) of cases, with spironolactone being the most frequent (11.1%, n=144). An oral retinoid and traditional immunosuppressive medication was used by 14.1% (n=183) and 8.7% (n=113) of participants, respectively. Participants underwent procedural treatment in 82.8% (n=1,075) of cases. Most frequent procedures were incision and drainage (70.0%, n=909), excision (54.8%, n=712), laser hair removal (10.5%, n=136), and deroofing (9.0%, n=117).

Discussion

To the best of the authors' knowledge, the analysis presented herein represents the largest and most comprehensive multinational study of patient perspectives on unmet needs in HS. A number of disease-related observations warrant discussion.

While nearly all Global VOICE patients had at least high school level education, approximately 10% were unable to find work. Approximately 15% also reported being disabled and unable to work due to their disease. Previous cohort studies have described frequent absences from work and inability to properly perform responsibilities, in some cases resulting in unemployment,[7-9] and this has also result in a negative impact on personal finances.[8] Indeed, HS patients were more often observed to have low socioeconomic status (SES) in recent population studies.[10,11] While low SES may influence development of disease, the more likely directional relationship is that low SES, potentially by way of inability to acquire or maintain gainful employment, is a disease consequence. Direct and indirect socioeconomic impact of HS warrants further study.

Most patients visited a physician at least five times prior to receiving a diagnosis, and they experienced on average a 10-year delay to diagnosis. Diagnosis delay reported herein is substantially longer than a mean delay of 7.2 years which was observed in a previous multinational survey.[12] Dermatologists likely have an important role in reducing diagnosis delay in HS, and indeed a dermatologist ultimately provided the formal diagnosis for over half of patients in this analysis. A dermatologist was also the main physician managing the disease in approximately 60% of patients. Care by a dermatologist has been shown to provide greatest likelihood of initiating medical treatment for HS, as well as for escalating therapy over time.[13] However, overall utilization of ambulatory dermatology encounters appears low, as only one in five HS patients in the US has an established relationship with a dermatologist.[14] Notably, half also reported disease flares either daily or weekly, and more than 80% experienced flares at least monthly. And yet, more than one third rated access to a dermatologist as difficult or very difficult, despite most living in urban or suburban areas. Not surprisingly then, one in four and one in six patients also reported visiting the emergency department and having been hospitalized, respectively, at least 4-5 times for acute symptoms. Utilization of acute care facilities, for which disease-

474 specific costs are high,[15-18] may be reduced further with improved urgent access to dermatologists. Along
475 with communicating the value of dermatologists in diagnosis as well as acute and ongoing management
476 of HS, there may be a need to ensure timely access to a dermatologist with the goal of improving quality
477 and cost of care.

478 In an international delphi exercise to define the core outcome set for clinical trials in HS, patients
479 selected pain as their most important symptom.[19] Remarkably, nine in ten Global VOICE patients
480 described recent pain associated with their disease, while six in ten rated this pain as moderate to worst
481 possible. In another study, recent pain was reported by 77.5% of patients and was linked to a substantial
482 decrease in QOL.[20] Specifically, pain and discomfort have been shown to interfere with daily activities,
483 work, school or leisure, and result in feelings of helplessness and dependency.[21] Chronicity of pain may
484 also be a significant factor related to misuse of substances, which was reported by approximately 4% of
485 Global VOICE patients. In a previous population analysis, prevalence of substance use disorder among
486 HS patients was also observed to be 4%.[22] However, strategies for addressing HS-associated pain are not
487 well established. If pain is addressed at all, there is likely to exist variations in pain management
488 practices,[23-25] which may contribute to substance abuse among HS patients. Development of appropriate
489 and effective pain management strategies for HS patients represents a fundamental unmet need. The
490 authors underscore that observations on substance abuse in this study should not further stigmatize
491 patients who are afflicted with HS. Rather, our hope is that the medical community, including
492 dermatologists, will further embrace and engage integrated care plans which comprehensively support
493 their needs.

494 In this analysis, a significant proportion of HS patients described a moderate to extreme, overall
495 and domain specific impact on life related to disease. Our population assessment of life impact is
496 supported further through detailed qualitative assessment within tertiary-center cohorts in which HS
497 patients describe impairments in enjoyment and satisfaction with general activity; independence; self-
498 esteem and body image, stigmatization and isolation,[6,7,21,26-30] as well as feelings of self-consciousness,
499 embarrassment, shame, repulsion, or being unlovable related to malodorous drainage or visible areas of

500 involvement.[31] Given the many ways the disease impacts QOL, it is not surprising that disease-related life
501 impact appears to be more significant for HS patients compared to those with atopic dermatitis, psoriasis,
502 acne vulgaris, alopecia, among other disorders of the integument.[26,32-37] In consideration for the total well-
503 being of HS patients, evaluation and management should include addressing psychosocial aspects of the
504 disease through interdisciplinary care with behavioral health professionals who can address mental health
505 issues and support coping and resilience strategies.[38,39]

506 More than 80% of Global VOICE patients report having a comorbid condition. This observation
507 is supported by a growing body of literature which suggests that HS, as a chronic inflammatory disease,
508 may represent a bridge to comorbid illnesses. In a recent analysis, HS patients were observed to have
509 twice the overall comorbidity burden compared with patients who did not have HS, as well as a
510 significantly greater burden compared to psoriasis patients.[1]HS is thought to have similar comorbidity
511 burden to other systemic diseases including systemic lupus erythematosus, dermatomyositis, ankylosing
512 spondylitis, and rheumatoid arthritis.[1] Patients with HS who have Charlson Comorbidity Index (CCI) of at
513 least 5 had approximately five times the risk of 5-year mortality compared to those with CCI score of
514 zero.

515 With more than one in three patients reporting depression and/or anxiety, mood disorders
516 represented the most frequent comorbidity among Global VOICE patients. Prevalence of depression
517 within HS cohorts at referral centers ranges between 19.5% and 41.6%.[26,40-42] Population data exploring
518 the association between HS and depression also indicates a significant burden of mood disorder.[43-45]
519 Notably, approximately one in eleven patients in the current analysis also reported suicidal ideation or
520 attempt, which represents an alarmingly high frequency, especially in the context of a known association
521 between HS and completed suicide.[46]Mood disorders and suicidality among HS patients is likely
522 explained by the physical and psychosocial effects of the disease which result in poor QOL and low
523 optimism. Global VOICE patients described a number of additional comorbidities, which are further
524 supported by other population-based analyses,includingacne,[47] polycystic ovarian syndrome,[48] pyoderma

gangranosum,[49] inflammatory bowel disease,[50-52] lymphomas,[53] spondyloarthritis,[54] metabolic disease,[55-59] obstructive sleep apnea,[60] major adverse cardiac events,[3] sexual dysfunction,[61] substance abuse and chronic opioid use,[22,62] and Down syndrome.[63] Given a general lack of disease awareness in HS and of its comorbidities in medical communities, dermatologists may need to be proactive in making recommendations on relevant preventative and screening measures to interdisciplinary care teams.

Nearly half of Global VOICE patients were dissatisfied with current treatments, most commonly because of perceived poor efficacy and undesirable side effects. One third was also dissatisfied with procedural treatments. Thus, it is not surprising that nearly half of patients expressed low optimism for having satisfactory control of symptoms in the near future. There is however growing enthusiasm in the medical community for addressing treatment as a fundamental unmet need in HS. Recent investigative efforts to understand pathogenesis in HS, including immunologic aberrations,[64,65] genetic predispositions,[66] and microbiome alteration[67,68] have translated to therapeutic trials which show promise. The National Institute of Health's database of clinical studies (accessible at www.Clinicaltrials.gov) describes 19 active or planned medical and procedural interventional trials in February, 2019. In alignment with drug development programs, there is also an international initiative to develop a core set of measures for trials in HS with the goal of improving measurement of disease activity and treatment response, as well as of comparing therapeutic effectiveness. To date, Hidradenitis Suppurativa Core Outcome Set Collaboration (HISTORIC), a section of the International Dermatology Outcome Measures (IDEOM) organization that is further supported by the department of dermatology at Zealand University Hospital and the Cochrane Skin Core Outcomes Set Initiative (CS-COUSIN), has reached global stakeholder consensus on the core set of domains for HS trials,[69] and is working toward finalizing its core measures set, which include new instruments under development. Additionally, there are several searchable global medical and advocacy organizations in HS that facilitate peer-to-peer support, encourage scientific discovery, and support access to treatments.

There are important limitations to this analysis warranting consideration. Data was self-reported and may be subject to misinterpretation of questions and to recall bias. Since questionnaires were

administered through dermatology centers, patients with more active or severe disease may have been selected. While demographic characteristics of the surveyed cohort approximate those of other HS populations in North America and Europe,[43,70-72] our sample is non-random and uncontrolled. As such, results with modest directionality may be difficult to interpret. Complete case analysis has the potential to bias results when patients with missing data differ systematically from patients without missing data. However, analysis of missing data among survey participants showed that patients excluded due to any missing data had similar characteristics and responses to patients included in the analysis.

Through this study, we have augmented our understanding of existing needs for HS patients, and we have identified several unmet needs which require attention. Addressing unmet needs in HS **(Table V)** is likely to necessitate a shared vision of health for HS patients among all stakeholders including patients, experts, interdisciplinary physicians, scientists, industry, regulatory agencies, philanthropists, advocates, and policy makers.

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738 **Table I: Demographics and Clinical Characteristics of Global VOICE participants (N=1,299)**

Demographics	n (%)
Age	
18-30 years	368 (28.3)
31-40 years	428 (33.0)
41-50 years	317 (24.4)
51-60 years	151 (11.6)
61+ years	35 (2.7)
Gender	
Male	196 (15.1)
Female	1103 (84.9)
Race (US, Canada only, n=479)	
White	386 (80.6)
Black	65 (13.6)
Other	28 (5.8)
*Body Mass Index**	
Underweight or Normal Weight (BMI <24.9)	269 (20.7)
Overweight (BMI 25.0-29.9)	306 (23.6)
Obese (BMI $\geq$ 30.0)	724 (55.7)
Tobacco Smoking Status	
Active smoker	571 (44.0)
Former smoker	352 (27.1)
Never a smoker	376 (28.9)
Highest Education Level Achieved	
High school	464 (35.7)
College/university degree	550 (42.3)
Graduate school degree	210 (16.2)
None of the above	75 (5.8)
Employment Status	
Employed/Not looking for employment/Retired	985 (75.8)
Not employed, looking for work	125 (9.6)
Disabled, not able to work	189 (14.5)
Marital Status	
Single/Divorced	419 (32.3)
In a relationship/Married/Widowed	880 (67.7)
Region	
Europe	719 (55.4)
North America	493 (38.0)
Other[a]	87 (6.7)
Setting	
Urban	629 (48.4)
Suburban	338 (26.0)
Rural	332 (25.6)
Physician diagnosing HS	
Dermatologist	707 (54.4)
Primary care	265 (20.4)
Surgeon	141 (10.9)
Obstetrician/Gynecologist	61 (4.7)
Acute care physician (Emergency Medicine or Hospitalist	54 (4.2)
Other type of physician	53 (4.1)

Pediatrician	11 (0.8)
Endocrinologist	4 (0.3)
Urologist	3 (0.2)

739
740 HS- hidradenitis suppurativa
741 a – Includes Asia, Australia, Africa, and South America
742 * Body Mass Index calculated from self-reported height and weight

Table II: Disease-related Quality of Life Impact Among Global VOICE Participants (N=1299)

	Not relevant	Not at all/slightly	Moderately	Very much / Extremely	Cannot engage due to HS
In the past one week, how much has your HS interfered with the following activities:					
Walking	72 (5.5)	720 (55.4)	259 (19.9)	227 (17.5)	21 (1.6)
Reaching	243 (18.7)	745 (57.4)	123 (9.5)	173 (13.3)	15 (1.2)
Standing up	125 (9.6)	851 (65.5)	185 (14.2)	133 (10.2)	5 (0.4)
Sitting down	73 (5.6)	651 (50.1)	253 (19.5)	308 (23.7)	14 (1.1)
Sleeping	64 (4.9)	679 (52.3)	252 (19.4)	292 (22.5)	12 (0.9)
Laying down	74 (5.7)	820 (63.1)	213 (16.4)	189 (14.5)	3 (0.2)
Leisure	93 (7.2)	496 (38.2)	230 (17.7)	348 (26.8)	132 (10.2)
Toilet	99 (7.6)	823 (63.4)	180 (13.9)	196 (15.1)	1 (0.1)
Shower	58 (4.5)	735 (56.6)	245 (18.9)	258 (19.9)	3 (0.2)
Dressed	53 (4.1)	726 (55.9)	224 (17.2)	290 (22.3)	6 (0.5)
Hair removal	205 (15.8)	388 (29.9)	164 (12.6)	336 (25.9)	206 (15.9)
Antiperspirant	236 (18.2)	587 (45.2)	112 (8.6)	193 (14.9)	171 (13.2)
Getting around	88 (6.8)	735 (56.6)	202 (15.6)	239 (18.4)	35 (2.7)
Exercising	143 (11.0)	444 (34.2)	193 (14.9)	326 (25.1)	193 (14.9)
Housework	71 (5.5)	624 (48.0)	232 (17.9)	336 (25.9)	36 (2.8)
Providing care	316 (24.3)	583 (44.9)	156 (12.0)	207 (15.9)	37 (2.8)
In the past one week, how much has your HS:					
Influenced your ability to work or study	159 (12.2)	606 (46.7)	181 (13.9)	274 (21.1)	79 (6.1)
Limited the type of work or study you do	175 (13.5)	623 (48)	153 (11.8)	275 (21.2)	73 (5.6)
Decreased the amount of time you spent on work or study	185 (14.2)	643 (49.5)	155 (11.9)	253 (19.5)	63 (4.8)
Caused you to use extra effort to do your work or study	174 (13.4)	604 (46.5)	144 (11.1)	319 (24.6)	58 (4.5)
In the past one week, how have your current or potential new HS lesions influenced:					
Clothing choice to avoid discomfort	38 (2.9)	311 (23.9)	207 (15.9)	743 (57.2)	N/A
Clothing choice to avoid visibility of HS	101 (7.8)	463 (35.6)	141 (10.9)	594 (45.7)	N/A
Clothing choice to avoid an HS Flare	54 (4.2)	383 (29.5)	193 (14.9)	669 (51.5)	N/A
In the past one week, how bothered have you					

been by these HS symptoms:					
Pain	18 (1.4)	446 (34.3)	315 (24.2)	520 (40.0)	N/A
Fatigue	58 (4.5)	462 (35.6)	276 (21.2)	503 (38.7)	N/A
Itch	39 (3.0)	526 (40.5)	303 (23.3)	431 (33.2)	N/A
Flu-like	130 (10.0)	898 (69.1)	144 (11.1)	127 (9.8)	N/A
Drainage	39 (3.0)	523 (40.3)	307 (23.6)	430 (33.1)	N/A
Odor	44 (3.4)	697 (53.7)	228 (17.6)	330 (25.4)	N/A
Skin tightness	48 (3.7)	554 (42.6)	268 (20.6)	429 (33.0)	N/A
Red lumps or knots	25 (1.9)	319 (24.6)	301 (23.2)	654 (50.3)	N/A
In the past one week, how much has your HS caused you to feel:					
Depressed	50 (3.8)	568 (43.7)	226 (17.4)	455 (35.0)	N/A
Angry	57 (4.4)	610 (47.0)	211 (16.2)	421 (32.4)	N/A
Embarrassed	69 (5.3)	532 (41.0)	213 (16.4)	485 (37.3)	N/A
Irritable	55 (4.2)	578 (44.5)	225 (17.3)	441 (33.9)	N/A
Anxious	89 (6.9)	605 (46.6)	204 (15.7)	401 (30.9)	N/A
Lonely	91 (7.0)	713 (54.9)	154 (11.9)	341 (26.3)	N/A
Withdrawn	77 (5.9)	422 (32.5)	169 (13.0)	631 (48.6)	N/A
In the past one week, how much has HS impacted your sexual activity:					
Lack of desire	171 (13.2)	407 (31.3)	130 (10.0)	453 (34.9)	138 (10.6)
Embarrassment	177 (13.6)	354 (27.3)	138 (10.6)	529 (40.7)	101 (7.8)
Pain	187 (14.4)	437 (33.6)	144 (11.1)	427 (32.9)	104 (8.0)
In the past one week, how much has your HS impacted your concentration (i.e., leisure, school or work):	N/A	676 (52.0)	298 (22.9)	325 (25.0)	N/A
In the past one week, how much has your HS impacted your life:	N/A	383 (29.5)	353 (27.2)	563 (43.3)	N/A

Table III: Frequency of Self-reported Comorbidities Among Global VOICE Participants

Comorbidity	n =1299 (%)
Anxiety	470 (36.2)
Depression	465 (35.8)
Obesity	456 (35.1)
Acne	405 (31.2)
Hypertension	194 (14.9)
Polycystic ovarian syndrome*	157 (14.2)
High cholesterol	146 (11.2)
Disability	132 (10.2)
Diabetes mellitus	117 (9.0)
Suicidal ideation	103 (7.9)
Infertility	74 (5.7)
Spondyloarthritis	72 (5.5)
Suicidal attempt	55 (4.2)
Crohn's disease	47 (3.6)
Substance use	47 (3.6)
Sexual dysfunction	46 (3.5)
Alcohol abuse	33 (2.5)
Ulcerative colitis	25 (1.9)
Myocardial infarction	12 (0.9)
Pyoderma gangrenosum	10 (0.8)
Coronary artery disease	9 (0.7)
Down syndrome	7 (0.5)
None	232 (17.9)

* Percent of female patients (n=1,103)

Table IV: Frequency of Current or Past Medical Treatments and Procedures Among Global VOICE Participants

Medical Treatment	**n=1299** ***(%)***
Antibiotic, oral	1,112 (85.6)
Intralesional corticosteroid	323 (24.9)
Biologic	270 (20.8)
adalimumab	208 (16.0)
infliximab	106 (8.2)
etanercept	25 (1.9)
secukinumab	15 (1.2)
ustekinumab	16 (1.2)
Anakinra	10 (0.8)
ixekizumab	5 (0.4)
Anti-Androgen	165 (12.7)
spironolactone	144 (11.1)
finasteride	26 (2.0)
Retinoid, oral	183 (14.1)
isotretinoin	150 (11.5)
acitretin	49 (3.8)
Immunosuppressive, traditional	113 (8.7)
methotrexate	88 (6.8)
cyclosporine	35 (2.7)
Mycophenolate mofetil	10 (0.8)
Systemic, miscellaneous	92 (7.1)
dapsone	60 (4.6)
zinc	24 (1.8)
oral contraceptive pill	11 (0.8)
cannabis	5 (0.4)
None	38 (2.9)
Procedural Treatment	1,075 (82.8)
incision and draining	909 (70.0)
excision	712 (54.8)
laser hair removal	136 (10.5)
deroofing	117 (9.0)
CO2 laser treatment	84 (6.5)
photodynamic therapy	13 (1.0)
None	224 (17.2)

*Sum of counts for individual medications may exceed the overall count for that category if a patient reported use of multiple medications within a category.

Table V. Addressing Unmet Needs in Hidradenitis Suppurativa

Domain	Unmet Need	Mechanisms to Address Needs
Diagnosis and Care	Disease awareness	●Promote advocacy and interdisciplinary education through patient support groups and medical organizations; Research and peer-reviewed publication.
	Delay in diagnosis	●Develop a point of care diagnostic aid which facilitates distinction from abscess or inflamed epidermal cysts by non-dermatologists. ●Promote the role of the dermatologists in diagnosis and management.
	Quality and cost of care	●Improve dermatology access to manage disease flares.
Symptoms	Control of symptoms	●Develop appropriate and effective management strategies to address pain, drainage, odor, fatigue and flare
Life Impact	Assessment of life impact	●Develop a disease-specific quality of life instrument to measure life impact
	Mental wellness	●Address psychosocial impact of the disease through interdisciplinary care with mental health professionals and advocates of well-being
Comorbid Conditions	Associated diseases	●Advance research to identify associated conditions, their related mechanisms, and their modification with treatment ●Develop guidelines on evidence-based recommendations for prevention and screening of associated conditions ●Establish interdisciplinary care teams to provide comprehensive care
Treatment	Safe and effective treatment	●Develop reliable and feasible tools to measure disease ●Develop relevant outcome measures to assess efficacy of treatments ●Advance research to identify disease mechanism and potential therapeutic targets ●Develop medical treatments with improved efficacy and safety profiles ●Evaluate outcomes for procedural treatments ●Develop guidelines for pain management